Cite this article as:
C N Peterson
The clinical, intellectual, ethical, and political
costs of biomedical research
Health Affairs 5, no.2 (1986):87-95
doi: 10.1377/hlthaff.5.2.87

The online version of this article, along with
updated information and services, is available at:
http://content.healthaffairs.org/content/5/2/87.citation

For Reprints, Links & Permissions :
http://content.healthaffairs.org/1340_reprints.php

Email Alertings :
http://content.healthaffairs.org/subscriptions/etoc.dtl

Not for commercial use or unauthorized distribution
To Subscribe: https://fulfillment.healthaffairs.org
The cost of biomedical research increased dramatically in the 1950s and 1960s leveled off in the late 1970s and early 1980s and now is at risk for major reductions as renewed attempts are made to balance the federal budget. The dollar cost of biomedical research is obviously of great importance, especially today, as many worthy and attractive federal programs find themselves for the first time in direct competition for funding. While acknowledging the importance of the direct economic cost of scientific investigation, this discussion will seek to enlarge the question of cost to include the clinical, intellectual, ethical, and political costs of doing or not doing biomedical research.

Questions To Explore

A number of questions that deserve exploration include: (1) Do health services currently available pose a major cost problem? (2) Has biomedical research resulted in a net increase in the costs of medical care? (3) Does fear of the potential cost of the clinical application of successful research run the risk of inhibiting biomedical investigation? (4) What are we prepared to do if a new medical technology is both very effective and very costly? (5) Is it possible to pay for desirable and effective technologies through economies in our present system of health care delivery? (6) Are we willing to grapple with the ethical, political, and intellectual issues or costs that lie at the heart of “doing science?” (7) For the purpose of highlighting the cost of “death prevention” (the other categories of health care cost being disease prevention and disease/aging modification), would it be instructive to define in part an ideal lifetime in terms of its complement, the ideal “death time?” (8) Finally, why do we appear to be avoiding generally rational and humanitarian decisions about the quality of life and quality of death to which we subject ourselves individually, familialy, and as a society?

Costs of health services. Health services currently available pose a major cost problem. Whether measured by the rise in the share of the gross national product (swelling from a 5 percent to a 10 percent share of the gross national product in the last twenty years and now pushing 12
percent), in federal Medicare deficits, personal health care insurance premiums, or in the cost of catastrophic illness (from intensive care for fragile neonates to multisystem failure in the aged), the cost of health care is large and at some point could become unaffordable by our nation if, for instance, it were to double as a percent of the gross national product by the year 2000. While the amount America should allocate to health care can be debated, the amount we can allocate to health care and survive as a nation in a world-competitive economy is much less amenable to humanitarian speculation. Some health costs are in fact discretionary, and some discretionary in theory only. In practice, neither the average individual level of awareness nor societal norms and accompanying laws permit thoughtful discretion at the time of life-threatening situations. Undeniably, we are now able to provide more in health services than we can pay for, in part because we have chosen to benefit widely from medical science and technology, and in part because of the imperative we Americans have assumed. If we are capable of doing something, we are apt to do it whether or not we would choose to do so on a fully discretionary basis—a technological imperative medicine shares, incidentally, with the nuclear arms race.

Biomedical research costs. The results are mixed regarding biomedical research’s contribution to the costs of medical care. Vaccines against polio and other infectious diseases have reduced the costs of acute and chronic care enormously. Reduction in the incidence of once common diseases such as tuberculosis, rheumatic fever, and glomerulonephritis, along with many other antibiotic-sensitive diseases, has similarly lowered the direct costs of illness and the costs of lost productivity. On the other hand, organ transplants, renal dialysis, cancer chemotherapy, hospital-based intensive care (especially preterminal care), and the like have increased dramatically the costs of care. It is beyond the scope of this discussion to assess with any accuracy the net effect of the countervailing forces that have increased and decreased health care costs. Biomedical research is a force, to be sure. So is the rise in the American expectation of more egalitarian utilization of available care. It is sufficient to say that to date, extended life and productivity may or may not have paid, in strictly economic terms, for the cost of the care that made them possible. But it is possible and even likely that the net cost of health care could increase markedly as a result of biomedical research.

Costs of clinical applications of research. Does fear of the potential cost of the clinical application of successful research run the risk of inhibiting biomedical investigation? Much of the vigorous ethical discussion that has surrounded new organ transplant research (liver, pancreas, lung, and the like) and the artificial heart centers on the fear that they might succeed. If they do, many wonder, can we pay for their widespread application, or can we devise acceptable guidelines to ration their use? If soci-
ety is unsure of its ability to pay for or otherwise allocate costly services, it will be but a next step, consciously or unconsciously, to inhibit research presumed to pose such a threat.

**Rationing costly technology.** What are we prepared to do if a new medical technology is both very effective and very costly? For the sake of discussion, presume that one or a series of new treatments or procedures is highly effective and so costly that it cannot be paid for by a majority of the people who would benefit from it. Would we as a society be willing to decide—through informal or formal means—that we will provide a high-cost therapy to those with the most to gain from it or the capacity to pay, or on some other arbitrary criteria, rather than deny it to all on the basis of egalitarianism?\(^1\) This challenge would be a severe test of our social fabric when there is no current evidence of any general agreement on pertinent social assumptions. But the economic challenge is only one piece of the problem. We are faced with an even larger metaphysical threat to our society. Have we considered the intellectually stultifying consequences to a free society of stopping biomedical research because of speculative fears about its economic ramifications? And just as we risk intellectual paralysis if we fear unpredictable scientific research, we also suffer another form of paralysis in the face of an imperative that has rendered us largely incapable of dealing with technologically driven prolongation of unwanted life.

**Paying for new technologies.** There are almost certainly ways to realize savings in our present system of health care that will enable us to pay for desirable and effective new technologies. First, we still fail to subject new technology to rigorous assessment prior to widespread clinical application. There are many examples of assessment failure: internal mammary ligations and gastric freezing in the 1950s stomach bypass for morbid obesity and coronary artery bypass for marginal ischemia at present.

Second, the cost-benefit analysis of many procedures is yet to be pursued stringently. A reduction in routine chest x-rays prior to hospital admission and mandatory post-trauma skull films are examples of potential savings in cost and perhaps in morbidity as well. We can look more carefully at the use of repeated ultrasound in normal pregnancies, routine circumcision, laboratory tests ordered randomly rather than to answer therapeutic questions, and the decision to perform elective surgery in the elderly patient with a short life expectancy. These and many more issues are not yet sufficiently explored in medical practice.\(^2\)

Third, the cost savings that lie within the reach of preventive medicine could well pay for the foreseeable cost of validated new technologies. Appropriate diet, tobacco avoidance, reduction of alcohol and substance abuse, rational exercise, and genetic screening and therapy all constitute the new promise of preventive medicine.

Finally, reorganization of the practice of medicine to eliminate eco-
nomic disincentives already has begun to link better care with economic advantages. There will always be, of course, the problem of the “common,” the conflict posed for individual incentives by the common use of resources, that is, the classical communal use of the New England town common for animal grazing. In this situation, overgrazing benefits the individual herdsman short term (“I fatten my cow”) and adds no disproportionate cost long term beyond that paid by all users for the damage done by overgrazing. Long-term benefit accrues to the individual only when restraint in grazing practice is exercised universally on the common (“All our cows are lean but alive”). In health care, any general saving achieved by forgoing even marginally advantageous but expensive individual services does not accrue to one’s personal benefit until all members of the “common” (society, a health maintenance organization, an insurance group) forgo high-cost marginal benefits simultaneously and equally.3 A comforting aspect of the issue of the medical common lies in the irony that more often than not, less care is better than more care.

Wrestling with ethical, political, and intellectual issues. Are we willing to grapple with the ethical, political, and intellectual issues or costs that lie at the heart of “doing science?” What are the actual or ultimate costs of doing or not doing biomedical research? It is easy to confuse the costs of research with the costs of clinical development, commercialization (in the case of products), and widespread clinical use. They are very different processes. The recent total cost of noncommercial public and private biomedical research funding has been less than $15 billion per year. In 1984, the total cost of personal health care (the sum of hospital, physician outpatient, drugs, custodial, eyeglasses, appliances, psychological counseling, and chiropractic services) in America was $341.8 billion.4 The immediate costs of research are relatively small, and not themselves a cause for alarm as an element in the total health care bill. It is clinical practice which is expensive. Therefore, there is little immediate logic in curbing research costs as a way of curbing health care costs, except for the fact that clinical costs in part have risen on the shoulders of the new technology spawned by research. Stop research, the argument goes, and you stop high-cost health care. Restated more precisely, stop research in expensive areas of investigation and you stop increases in high-cost health care. The problem with such logic is that it fails to acknowledge the nature of research, a process that essentially does not and cannot predict its intended results, and certainly not its secondary economic effects. Results of research are unpredictable both scientifically and economically. It might be useful to construct a visual schema to clarify how research flows to clinical care. (See Exhibit 1.)

It should be clear that it is difficult or impossible to predict the initial economic consequences of biomedical research. It would be even more difficult to predict which high-cost technology will become a low-cost technology given time for refinements, further research, and mass pro-
Exhibit 1
The Flow Of Research

An idea

Search of the literature

A research protocol

A funded research protocol

Negative results:
1. Redirected research
2. Useful negative data
3. Serendipity
   (an unplanned discovery)

Positive results:
1. No immediate clinical application (99%)
2. Clinically useful therapy or procedure (1%), producing the following range of bioeconomic scenarios:
   a. Low-cost therapy with a large savings over existing options or conditions (for example, polio vaccine, penicillin, informed tobacco choice, and aseptic water, milk)
   b. High-cost therapy with variable savings over existing options or conditions (for example, artificial hip replacement vs. prolonged invalidism and cerebral CAT scan vs. possibly toxic invasive studies)
   c. High-cost therapy which replaces no existing therapy (for example, organ transplantation, artificial car, and artificial heart)

duction. Not so long ago, computers were room sized and cost millions. Today, equally sophisticated computers are portable and cost hundreds of dollars. Within medicine, the cardiac pacemaker and automated blood test systems are two case studies in miniaturization and cost savings. If genetic recombinations produce insulin, growth hormones, or any of a myriad of such substances, the cost savings and mass production possibilities will be remarkable. Clearly, the economic results of research are even more difficult to predict than the scientific ones.

There is a larger concern, albeit more metaphysical than economic. Imagine a scenario wherein national research policymakers become fearful of the capacity of a free society to deal with possible high-cost commercialization of biomedical research successes, such as a working comfortable artificial heart, pancreas, ear, and joint for all in need. In addition to the unpredictability of ultimate costs as discussed, in addition to the issue of rational or rationed utilization of scarce resources, consider simply the cost of suppressing research in a free society. At what point will the success of an idea be deemed to be economically dangerous? Can we safely stop research when its preliminary results portend high-cost success? Given popular interests in a democratic society, it is unlikely that the embryonic genie of an unleashed idea can be stuffed back in the lamp (of unfunded research proposals).
If not at the level of funding, where would we stop research inquiry? It seems likely that our society will be forced to earlier and earlier suppression of research and the imagination which lies behind it if we were to be successful in avoiding the possibility of economically indigestible success. Could this ultimately lead to a Galileo effect, namely, that it is too late for a timid or threatened society to stop research after it has begun? If it is to be stopped it must be stopped before it gains interest or momentum. Galileo recanted with respect to the movement of the earth and sun, but the ideas he and Copernicus released in the sixteenth and seventeenth centuries could not be restrained. And of course if we could restrain such ideas today, what would that say for the future of our society?

Before concluding this discussion of the economic unpredictability, impracticability, and high intellectual cost of suppressing research, it is important to answer those who would refuse funding to research with theoretical high-cost potential but instead fund therapeutic programs with low-cost mass applications. Such well-intended reallocators would fund nutrition or antismoking campaigns with money saved from research on liver transplantation. This fungibility argument seems both attractive and plausible, but it never seems to work. Unless Gramm-Rudman-Hollings changes our political psychology, there appears to have been little evidence of the transfer of funds from an attractive area of investigation or care to a politically unattractive area, even assuming both areas have scientific merit.

Lifetime and “death time.” For the purpose of highlighting the cost of “death prevention” (the other categories of health care cost being disease prevention and disease/aging modification), would it be instructive to define in part an ideal lifetime in terms of its complement, the ideal “death time?” To have died well in terms of timing, care, dignity, cost, and accomplishment is by definition to have lived well. The highest biologic or demographic good is met by dying quickly and inexpensively after your social order has reproduced sufficiently to perpetuate the species. The highest economic good is met by dying cheaply after you have ceased to produce more than you consume. (How shall we value a grandmother’s story?) The highest personal good is met by dying painlessly and cheaply after you have ceased to experience joy, inspiration, wisdom, or growth. The highest ideologic good depends upon your view of the purpose of mortality, with the preferred lifetime varying from almost endless biologic viability at any cost at one extreme to an existential idiosyncratic norm at the other. In between lie the many varieties of religious interpretations of mortality. The pluralism appropriate to such a range of interpretations is not at present reflected in a corresponding range of acceptable legal or social norms.

Quality of life and quality of death. The final consideration with respect to the costs of biomedical research rests with the question as to
why generally rational and generally humanitarian decisions are not being made routinely about the quality of life and quality of death to which we subject ourselves individually, familially, and as a society? The Judeo-Christian tradition of the West had no biomedical technology to deal with at its origin, indeed not until the emergence of modern medicine in the late 1930s. Our ethical values with respect to the preservation of life are grounded in an era when acts of commission akin to murder (as opposed to acts of omission) were the only unnatural factors altering the life span which were subject to consideration.6

Consideration of the economic cost of prolonging of life beyond rational or humanitarian limits raises a chilling specter. Are we suggesting that at a certain point the life of self, family, or fellow citizen becomes too expensive to sustain? That may be true, but it should not and need not be at the center of the argument. Rather, we can ask the more proximal question: What quality of life shall we expect before we allow a life to slip away by an act of omission, that is, by denying technological assistance? An act of omission allows a vegetative Alzheimer’s patient to die of pneumonia, which the administration of penicillin would likely cure.7 Another act of omission would allow a terminal cancer patient to die of dehydration. Either demise can occur in relative comfort over one to four days. It can be argued that to employ penicillin or nasogastric/intravenous hydration tubes is to pay an unnecessary cost of biomedical research. A thorough examination of the cultural and technologic origins of our attitudes toward murder and suicide are beyond the scope of this discussion, but it is appropriate to define generally such a medical act of omission. It is simply the humanitarian withholding of a product of biomedical research, an omission which in no way appears to conflict with the Judeo-Christian tradition of our legal and cultural prohibition of murder.

The admitted difficulty in defining legally a reasonable or acceptable quality of life need not prevent society from recognizing a long continuum which starts with full health and trails off into noncerebral vegetative life at one extreme and into agonizing highly alert but incurable cancer at another. Are we justified in choosing not to deal with such extremes because we are uncertain and fearful about the areas of gray? The act of writing a so-called living will at a time of mental and emotional competency has helped many people to inform family and professionals of their preferences to avoid life-prolonging technical maneuvers in the face of irreversible terminal disease. Yet such a document is often difficult to interpret legally under changing circumstances. It may be important for patients to learn (and physicians to gently suggest) that deliberate preterminal discussions can take place involving the patient, responsible family or friend, and chosen practitioner. These discussions can occur months or years before the onset of terminal disease, with the goal to insure that each of the parties clearly understands the wishes of
the patient and indicates his or her willingness to be involved in non-initiation or cessation of unwanted therapy (an act of omission) at times and situations and in ways which have been described and agreed upon. Such preterminal clarification of a patient's preferences is required if the family and the practitioner are to be prepared with sufficient understanding of and confidence in the patient's intentions. Undoubtedly some practitioners will be uncomfortable about such discussions and understandings; if so, it is better to know early so the patient and family will have time to find a practitioner who will feel able and comfortable with that involvement. It should be emphasized that there is little need or value in endowing such discussions with legal authority and trappings beyond perhaps the keeping of brief professional notes and the generation of the living will. The important process is communication and clarification and preparation for the role that each element of this most human equation is to play in insuring freedom from unnecessary pain and unnecessary prolongation of what is unhuman and undesired. A living will can be a useful part of that process. The before-the-fact discussion has the critical value of helping patients come to an understanding of their own true feelings. It is acknowledged that many patients will nor choose to undertake such a primal task and others might choose to do so intellectually but be unprepared emotionally for the process. The point is not that any patient should be obliged to undertake medical death planning. Rather, it is that all patients should become acquainted with the option and way to accomplish such a process.

In contrast to a situation where unwanted life goes on and we are paralyzed to stop it, fear of the economic consequences of successful biomedical research has the potential to produce an opposite public policy dilemma: stop research and stop thought, for fear of the cost. Ultimately, biomedical research engenders a mosaic of costs—economic, intellectual, ethical, and political. Our brilliant record of biomedical successes has taken us to two ethical and intellectual crisis points as we contemplate the future of biomedical research. Will we have the societal will to economize health care costs so that we are able to pay for the technological medical miracles that lie before us? If we lack the wit or will to use our health care dollars wisely, will we be forced to either ration painfully and perhaps unsuccessfully what we have left to spend, or worse, shackle the free minds which would produce those miracles? The immediate answer lies in assessment, prevention, and incentives, not in exclusion or stultification.

Further, if we allow ourselves to be victims of a mindless technological imperative with respect to the quality of life and death to which we will subject ourselves, we risk becoming twenty-first century Luddites who will smash (intellectually and politically) the very machines we created to free ourselves—ironically, misguidedly, and unnecessarily—from the mis-use of their benefits.
Summary

There is a great deal right with health care in America as measured by widespread access to advanced medical care, both corrective and preventive. Since we entered the era of scientific medicine, some fifty years ago, however, the health care relationship has been increasingly one-directional, that is, what active science and science practitioners have done for largely passive patients. This paper has focused on three issues or problems whose solutions will rest with the consumer and citizens-at-large as much as or more than they will with health care professionals or with the science they dispense. First, can we realize the large potential savings in health care cost by better assessment before new technologies become popularized, by further improvement in life-style and preventive medicine, and by the incorporation of cost-saving incentives into routine care? Second, in the face of potential economic and ethical problems associated with research success, can we sustain a national faith in the value of new knowledge and specifically in health care solutions through biomedical research? Third, can we restore a balance between our capacity to live with the benefits of science and our capacity to die without the impediments of science and judge that balance on the basis of humanitarianism, common sense, and the right to omission rather than on technical or legal imperatives? All three of these issues are interconnected and will require serious attention if the quality of our lives and our spirit of inquiry are to avoid falling victim to the cost, the fear, and the unwarranted imperatives of the very science that has enriched us.

NOTES

1. As Aaron and Schwartz have observed in England, there appears to be an informal consensus that after a certain age a person is just too “crumbly” to warrant high-tech, high-cost regimens such as renal dialysis. See Henry J. Aaron and William B. Schwartz, Painful Prescription: Rationing Hospital Care (Washington, D.C.: Brookings Institution, 1984).
5. Accomplishment for this purpose can be defined as genetic, intellectual, cultural, and perhaps spiritual productivity and reproductivity.
7. Before antibiotics, pneumonia was known as the “friend of the aged” for its capacity to hasten the demise of the terminally ill.